

# **IMMUNIZATION REGISTRY FOCUS GROUP STUDY**

**September 22, 1998**

**Monolingual Hispanic, Lower education**

**Tucson, Arizona**

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## **SECTION 1: GENERAL IMMUNIZATIONS AND HEALTHCARE**

### **I. Prevention**

Diseases mentioned:

- Polio
- Chicken pox
- Measles
- Hepatitis
- Whooping cough (Tosferine)
- Mumps

### **II. Immunization**

#### **A. *Reasons not to get vaccinated***

- Lack of responsibility
- Fear
- Religion
- Lack of time
- Difficulties with transportation

#### ***Reasons to get vaccinated***

- To avoid getting ill
- It is socially irresponsible not to

#### **C. *Ways parents are reminded of vaccine schedule***

- Personal record card given to new parents
- Reminder calls or letters from doctors and/or clinics
- Reminders from schools
- Information on radio and television

#### **D. *Methods of easier tracking***

- Mark on calendar when vaccine is due and when to make appointment for next vaccine.

- Call doctor or nurse when unsure.

## **SECTION 2: IMMUNIZATION REGISTRIES**

### **I. Initial reactions to the idea of a registry**

#### ***Positive reactions:***

- The registry would be useful for people moving to another state.
- Doctors will have the same information and, thus, will be able to advise parents about what is needed and/or missing.
- Registries will offer choices for sources of information about immunizations for children.
- Registries will provide for retrieval of information when other records are lost.
- Information will be readily available in case of emergency.
- Adverse reactions and allergies will be noted and available to doctors.

#### ***Negative reactions/concerns:***

- People not directly involved with these parents' children would have access to registry information.
- Information will not be confidential.
- People might take advantage of, falsify or abuse the information. (Note: This was an important concern that was shared by respondents who had prior experience with the abuse of their personal information, especially with the copying of their Social Security numbers.)

#### ***Other concerns:***

- Will the registry be computerized?
- How does one obtain information from the registry?
- Will proper identification be required in order to obtain information from the registry?
- Would members of the extended family have access to registry information?
- Would parents be able to authorize others to obtain information?

### **II. Content of the registries**

#### ***A. Initial reactions to the type of information typically in a registry***

- Respondents were ambivalent about the type of information filed in a registry. They were concerned that some people with access to the information might abuse or falsify it.
- Overall, respondents said they would be comfortable with the inclusion of the following information:
  - Date of the vaccination

- Manufacturer of the vaccine
- Vaccine lot number
- Type of vaccine
- Child's date of birth

**B. *Reactions to including home address and phone number***

- Most respondents felt this information would facilitate communication.
- A few felt this would be too much personal information.

**C. *Reactions to including parent or child Social Security number***

- Most respondents felt this information would eliminate confusion among children who have the same names.
- Many respondents felt that having the SSN on file would be helpful in case of emergency.
- Only a few respondents were negative about the inclusion of Social Security numbers. They felt these numbers should not be public information. They also felt that inclusion might make this information accessible to people who would falsify records or use the numbers themselves.

**D. *Reactions to including healthcare members enrollment (WIC, Medicaid numbers)***

- Respondents were positive about including Medicaid numbers because similar information is noted there.
- They were not familiar with WIC.

**III. Access**

**A. *Who should have access***

- Parents
- Doctors
- Legal guardians
- Grandparents
- School and nursery administrators (in case of emergency only)
- When probed about researchers having access, most were comfortable with the idea.

**B. *Who should not have access***

- In-laws
- Neighbors
- Unauthorized extended family members

- In some cases, a divorced spouse (i.e. when the provision of information includes address and phone number).
  - When probed about insurance companies having access only one respondent raised the concern that insurance companies might raise their premiums.
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**C. *Reactions to linking registry by computer to other health information systems***

- There were no concerns about linking the registry with other health databases.

**IV. Consent and Inclusion**

**A. *Reactions to “opting out” option***

- Respondents were concerned that some information could be included without their authorization.
- They felt that they might not have sufficient time to respond or that their responses could be lost in the mail.
- Respondents felt this option would include more children and that children would not be excluded due to parental neglect.

**B. *Reactions to “consent” option***

- Most respondents preferred this option. They said this option made them feel secure and in control.

**C. *Reactions to “automatic” option***

- Most respondents disliked this option. They said it would make them feel mandated to and that they had no choice.
- Respondents said, however, that this option would ensure the safety of their children and would save parents the effort of enrolling the child.

**SECTION 3: WRAP UP AND CLOSING**

**I. Most important benefit(s) of registries**

- Fast, easy access for medical professionals
- Convenience
- Improved communications about immunizations
- Insurance against lost immunization records
- Assistance to physicians in emergency situations

- Notations about allergies and cross-reacting medications.
- When probed about reporting harmful reactions, several agreed this would be an advantage
  - When probed about reduced possibility of receiving the same vaccine twice many agreed this would be an advantage.

## **II. Greatest concern(s)/biggest risk(s)**

- The possibility that incorrect information be registered
- Breaches of confidentiality
- Accessibility of information to divorced parents (that custodial parent wishes to keep confidential)
- When probed about concerns over exclusion from school, denial of health benefits, government having too much information, and immigration issues, no one expressed great concern.

## **III. Influence of healthcare provider in decision to participate in a registry**

- Respondents felt that they, as parents, would be the primary decision-maker. Their doctors' recommendations would not weigh heavily on their decision to participate in a registry.

## **IV. Suggestions/comments to people who are responsible for how system works**

- *If it is for the well-being of our children, it is a very good thing. Thank you for caring and helping us.*
- *The registry is a good idea that will help me if I misplace or lose the information. It will be great to have a place where I can retrieve correct information.*
- *It would be convenient if hospitals and schools have this information readily available. It will increase the safety of my child.*
- *I would not like you to input my child's Social Security number, not if I am married or single, and not the name of the school my children attend.*
- *I would not want you to give this information to my ex-husband.*
- *I like the idea of the registry but have some concerns regarding how it will be used.*
- *This is a great idea, an excellent source of information for doctors and families and a great help for our community.*